

# FRAMEWORK FOR THE CONSIDERATION OF CHRONIC DEBILITATING CONDITIONS IN WOMEN

May 31, 2023 | Kathryn G. Schubert, MPP, CAE



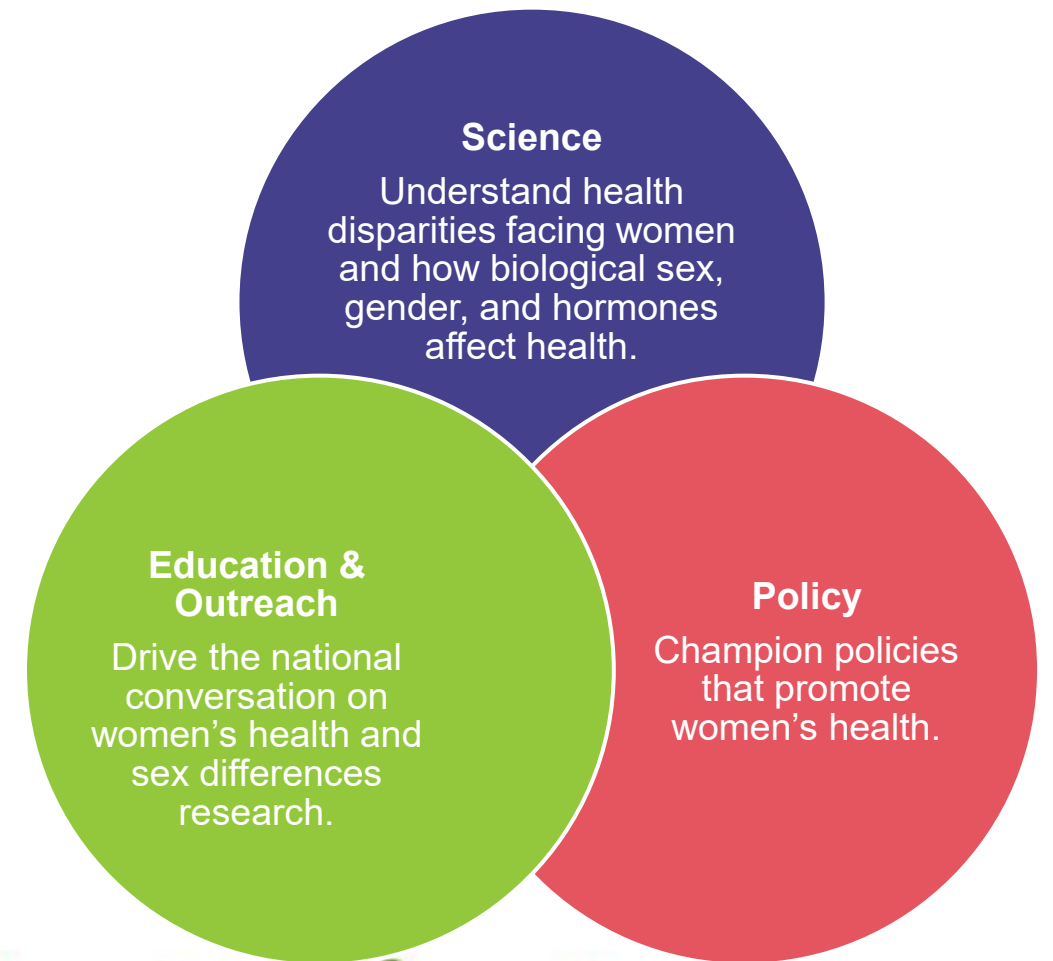
Society for  
Women's Health Research

## MISSION

SWHR is the national thought leader dedicated to promoting research on biological sex differences in disease and improving women's health through science, policy, and education.

## VISION

Make women's health mainstream.



# Applying SHWR's Core Pillars to Chronic Debilitating Conditions in Women

- Alzheimer's Disease
- Autoimmune and Immune-Mediated Diseases and Conditions (e.g., Arthritis)
- Cancers
- Endometriosis
- Fibroids
- Heart Health
- Infertility
- Menopause/Menopausal Symptoms
- Migraine

## SCIENCE

- Interdisciplinary roundtables
- Identification of research gaps and unmet needs
- Creation of deliverables addressing needs:
  - Academic publications
  - Clinician resources
  - Patient-facing toolkits
  - Roadmaps

## POLICY

- Source of guidance for policymakers
- Aiming to improve representation of women and sub-populations of women in clinical trials and across all levels of science
- Creation of deliverables addressing needs (e.g., policy agendas, fact sheets)
- Championing women's health at the federal level

## EDUCATION AND OUTREACH

- Trusted source of information on women's health
- Raise awareness of disparities and unmet needs in women's health
- Create engaging, scientifically-driven content for diverse audiences across multiple channels

# Current U.S. Landscape: Chronic Conditions in Women

## ***Takeaways from “Chronic Conditions in Women: The Development of a National Institutes of Health Framework”***

- Definitions of Chronic Conditions
  - Vary widely in heterogeneity in characteristics (e.g., duration, latency, need for medical attention)
  - Existing definitions do not incorporate sex or gender considerations
- Data
  - Sex and gender variables are not routinely disaggregated in reporting of clinical research
  - Widespread variations in prevalence of diverse chronic diseases, the number of hospitalizations for specific diseases, and the diagnosis and mortality rates for different states
- By available measures, research within the NIH has not mapped to the burden of chronic conditions among women.

# Gaps and Opportunities

- Representation in Clinical Trials
  - Women are still underrepresented in clinical trials
  - Subpopulations of women are still underrepresented in clinical trials
- Impact of SABV on Chronic Conditions in Women Across the Life Course
- Impact of Gender on Prevention, Diagnosis, and Treatment of Chronic Diseases Among Women
- Inadequate Framework for Studying Chronic Conditions
  - This is especially true when they involve multimorbidity
- Women's Research Workforce

# Factors to Consider When Prioritizing Research

- Potential health impacts (e.g., accounting for disease burden, prevalence, costs of care)
- Consideration of issue being addressed through other funding mechanism
- Feedback from stakeholders, including patients and health care providers

# Challenges: Research Funding Landscape and Possible Solutions

- Politicization of Science
- “Politics”
- Challenges with Data Variability
- Infrastructure for Research on Health of Women
  - RCDC Codes
- Addressing Implicit Bias

# THANK YOU

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